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ABSTRACT

This report discusses the results of an analysis of demographic and Client Development Evaluation Record data compiled at each of the 21 regional centers in California serving individuals with autism and pervasive developmental disorders. Data covering a period of 11 years, beginning in January 1987 and continuing through December 1998, show that the number of persons with autism grew markedly faster than the number of persons with other developmental disabilities. Significantly greater numbers of persons with autism are entering the regional center system. In the past year alone, 1,685 persons with autism were taken into the system. The number of persons entering the system far exceeds the expected number determined by traditional incidence rates. Estimates suggest that, compared to other disabilities, net growth in the number of persons with autism is on average about 3 percent greater each year. Compared to characteristics of 11 years ago, the present population of persons with autism is younger, has a greater chance of exhibiting no forms or milder forms of mental retardation, is more likely to live at home, and is more likely to receive an earlier diagnosis. Appendices include the diagnostic criteria for autistic disorder, Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified. (Author/CR)

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ED 431 255

Department of Developmental Services

Changes in the Population of Persons with Autism and Pervasive Developmental Disorders in California's Developmental Services System: 1987 through 1998

A Report to the Legislature
March 1, 1999

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EXECUTIVE SUMMARY

A. Purpose

Budget bill language (AB 1656, Chapter 324, statutes 1998) requires the Department of Developmental Services report to the Legislature on the incidence of autism and pervasive developmental disorders and compare the number of persons with autism to the other developmental disabilities as defined by Lanterman Developmental Disabilities Act (Division 4.5, commencing with section 4500, of the Welfare and Institutions Code). The report contains findings and conclusions that are based on an analysis of data provided by the regional centers to the Department for the period 1987 through 1998.

B. Description of Autism

Autism is a profound and poorly understood developmental disorder that severely impairs a person's abilities, particularly in the areas of language and social relations. Autistic children typically are normal in appearance and physically well developed. Their disabilities in communication and comprehension range from profound to mild. Historically, about 75 percent of persons with autism are classified as mentally retarded. Their most distinctive feature, however - which helps distinguish them from those solely mentally retarded - is that they seem isolated from the world around them.

Autism is manifest uniquely and heterogeneously in a given individual as a collection of symptoms which are rarely the same from one individual to another. Two children with the same diagnosis, intellectual ability and family resources are more likely to be recognized more for their differences than their similarities. Variation in the degree of impact on the individual is well documented and subtypes of the disorder have been identified. The professional community continues to work to clarify the confusion and controversy concerning the nature, causes, methods of diagnosis, and treatment of autism. As research has uncovered subtle differences in the onset and development of symptoms, different types of autism have been described. The current Diagnostic and Statistical Manual Fourth Edition (DSM IV), published in 1994, identifies five different disorders referred to collectively as the pervasive developmental disorders (PDDs).

C. Incidence of Autism

The most cited incidence statistic is that autism occurs in 4.5 of every 10,000 live births. This is based on large-scale surveys conducted in the United States and England. In addition, the estimate of children having autistic-like behaviors, i.e., when other disorders under the PDD umbrella are included, the incidence rate may go as high as 15 to 20 of every 10,000 live births. In this report the incidence of autism is not measured. The unit of measure reported here is the rate of occurrence of persons with autism or other PDDs in the regional center and developmental center system during a specified period of time. The main question addressed in this report is whether the number of regional center eligible persons with a diagnosis of autism has increased in comparison to the other Lanterman Act developmental disabilities: Cerebral Palsy, Epilepsy and Mental Retardation.

D. Findings

The findings and recommendations presented in the report are derived from analysis of demographic and Client Development Evaluation Record (CDER) data compiled at each of the 21 regional centers and forwarded electronically to the Department. Data covering a period of eleven years, beginning in January 1987 and continuing through December 1998, show that the number of persons with autism grew markedly faster than the number of persons with other developmental disabilities. Significantly greater numbers of persons with autism are entering the regional center system. In just the past year, there were 1, 685 persons with autism taken into the system. The number of persons entering the system far exceeds the expected number determined by traditional incidence rates. Estimates suggest that, compared to the other disabilities, net growth in the number of persons with autism is on average about 3 percent greater each year. Because the current trend has continued for the past several years, it suggests that relatively faster growth in the number of eligible persons with autism will continue. Compared to characteristics of 11 years ago, the present population of persons with autism are younger, have a greater chance of exhibiting no or milder forms of mental retardation, are more likely to live at home, and are more likely to receive an earlier diagnosis.

E. Conclusions

This report was not an investigation of incidence, but was rather an official counting and reporting of the numbers of persons with autism and other developmental disabilities served by the regional center system over time. This report does not include any data on those persons in California who are not part of the Developmental Services system. The Department's CDER data provide evidence that support the following two general statements: (1) the number of persons entering the system with autism has increased dramatically over the past 11 years relative to the other three developmental disabilities, and (2) the accelerated rate appears to be sustaining an upward trend into future years. In light of the information presented in this report, it is reasonable to assume that the population of persons with autism will continue to rise faster, relative to the other developmental disabilities. A valid ascertainment of the incidence of autism and other PDDs could not be made. However, the persistent and apparently stable increase in intake rates of persons with autism is justification for further and accelerated scientific study. Unfortunately, the quality and type of information examined in this report were not suitable for measuring incidence in the population of persons with autism. Ascertaining the incidence for autism and the other PDDs will require carefully controlled research. Furthermore, it is far beyond the capability of this Department to undertake such studies. Independent study of the factors that have contributed to the increase in the population of persons with autism needs to be conducted by academic institutions and medical researchers with the experience and knowledge necessary to conduct such research.

I. Introduction

This report constitutes the response of the Department of Developmental Services to legislative directives contained in the 1998-99 Budget Act for Item 4300-101-0001, provision 9. The specific requirements are that:

> The State Department of Developmental Services shall survey all regional centers and secure data from the data base of the department to ascertain the incidence of autism and pervasive developmental disorders in California. The department shall compile the number of persons who entered the regional center system during the period between January 1, 1988, to January 1, 1998, inclusive, with the diagnosis of autism and pervasive developmental disorders. The survey shall include a comparison during the period between January 1, 1988, to January 1, 1998, inclusive, of the numbers of persons with each of the other disabilities as defined by the Lanterman Developmental Disabilities Services Act (Division 4.5 (commencing with Section 4500) of the Welfare and Institutions Code) and those diagnosed with autism and pervasive developmental disorders. The department shall report its findings to the Legislature by March 1, 1999.

In 1969, landmark legislation, AB 225 (Lanterman) Chapter 1594, was signed into law by governor Ronald Reagan; this later became known as the "Lanterman Developmental Disabilities Services Act"(California Welfare & Institutions Code, Section 4500-4519). Under the Lanterman legislation, "The State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge." This bill mandated that a network of regional centers be created throughout the State. In addition, it also mandated the regional centers to serve not only persons with mental retardation but also cerebral palsy, epilepsy, autism and other neurological conditions closely related to mental retardation.

Regional centers function as a service hub, coordinating, linking and funding services and supports in their local communities for all eligible consumers and their families. The California Legislature has established that developmentally disabled residents and their families are entitled to government (state and federal) funded services. Regional centers have an obligation to ensure that essential services are provided through generically funded public agencies or, in the absence of generic agencies, through regional center funding. Services offered by regional centers include outreach and case-finding, assessment and diagnosis, individualized planning and service coordination, information and referral, and brokering of services and supports from a network of community service providers. Additional services include advocacy, crisis intervention and resource development. There are 21 regional centers from San Diego to Eureka that serve each of the 58 counties in California. The total community population including high risk infants is more than 150,000. Approximately 3,930 persons reside in the five developmental centers.

II. An overview of Autism

A. Background

It has been more than 50 years since Dr. Leo Kanner, a psychiatrist at Johns Hopkins University, wrote the first paper applying the term "early childhood autism" to a group of 11 children who were self-absorbed and who had severe social, communication, and behavioral problems. In the 55 years since autism was identified, a great many developments in diagnostic and treatment methodology have occurred. In the past 20 years there has been an explosion in scientific research in autism. More than 10,000 articles with autism as the subject appear in the scientific literature. The clinical definition of autism and other pervasive developmental disorders has evolved with highly specific behavioral descriptions that cover each age and developmental spectrum. The diagnostic criteria that define autism are written to ensure that behavioral symptoms must be observed as distinctly deviant relative to the individual's developmental level or mental age. These refinements in the diagnostic criteria increase the chance of an earlier and accurate diagnosis. See Appendix B. for the early history of autism.

Additionally, sophisticated teaching and early intervention programs have been developed that offer realistic hope for long-term developmental growth in children with autism. All of these advancements have supported the desire of parents, professionals and advocates for timely and high quality services.

B. Characteristics of Persons with Autism

Autism is a profound, and poorly understood developmental disorder that severely impairs a person's abilities, particularly in the areas of language and social relations. In many cases the disorder is evident during the first 30 months of life. Autistic children typically are normal in appearance and physically well developed. Their disabilities in communication and comprehension range from profound to mild.

There is no single adjective that can be used to describe every person with autism because the disorder is manifest in many different forms. For example, some individuals are antisocial, some are asocial, and others are partially social. Some are aggressive toward themselves and/or aggressive toward others. Approximately half have little or no language. Perhaps 25 percent repeat (echo) words and/or phrases, and another 25 percent may be capable of acquiring nearly normal language skills. Since there are no medical tests at this time to determine whether a person has autism, the diagnosis of autism is given when an individual displays six of 12 characteristic behaviors that match the criteria in the Diagnostic and Statistical Manual, Fourth Edition (DSM IV), published by the American Psychiatric Association. Persons who present autistic behaviors but fail to qualify for six or more of the criteria can be diagnosed with PDD,NOS (Pervasive Developmental Disorder, Not Otherwise Specified).

Persons with autism, compared to other disabled persons of commensurate ability, are more difficult to teach. Comparatively, persons with autism have significantly greater problems acquiring and using language and relating socially. They are rarely able to work productively in

the mainstream of employment. Historically about 75 percent of persons with autism are classified as mentally retarded. Their most distinctive feature, however - which helps distinguish them from those solely mentally retarded - is that they seem isolated from the world around them, i.e., they sometimes appear detached, aloof, or in a dreamlike world. Many individuals oftern appear only vaguely aware of others in their environment, including family members. Another characteristic that differentiates autism from persons with a primary diagnosis of mental retardation is the much greater likelihood that the autistic person will display strange postures, mannerisms, habits, and compulsions. Ritualistic behavior, hand-flapping, unusual food preferences, absence of establishing eye contact, apparent insensitivity to pain, and self-injurious behaviors are sometimes seen in persons with autism. Appropriate play with other children or toys is uncommon. There is often a great interest in inanimate objects, especially mechanical devices and appliances.

III. Recent Developments in the Field and PDD

A. The Broader Definition of Autism

Autism has multiple causes and is manifest uniquely and heterogeneously in a given individual as a collection of symptoms which are rarely the same from one individual to another. Two children with the same diagnosis, intellectual ability and family resources are more likely to be recognized more for their differences than their similarities. Variation in the degree of impact on the individual is well documented and subtypes of the disorder have been identified. The professional community continues to work to clarify the confusion and controversy concerning the nature, causes, methods of diagnosis, and treatment of autism. As research has uncovered subtle differences in the onset and development of symptoms, different types of autism have been described. In recent years an effort has been made to reclassify autism as one type of pervasive developmental disorder (PDD). The term "autistic spectrum disorder" is frequently employed to acknowledge the diversity and severity of autism. As different types of autism have been identified through scientific research, the criteria for diagnosing these other types overlap with the definition of autism and tend to make autism more difficult to diagnose. In 1968, the American Psychiatric Association's definition of autism referred to a single disorder, not a syndrome of behavioral and medical effects as it is now known to be. The third edition of the Diagnostic and Statistical Manual, published in 1980, introduced the term "pervasive developmental disorders." The current Diagnostic and Statistical Manual Fourth Edition (DSM IV), published in 1994, identifies five different disorders referred to collectively as the pervasive developmental disorders. Those disorders include five separate diagnoses:

- Autistic Disorder, (299.00)
- Pervasive Developmental Disorder, NOS (not otherwise specified), (299.80)
- Asperger's Disorder, (299.80)
- Rett's Disorder, (299.80)
- Childhood Disintegrative Disorder, (299.10)

See Appendix A. for the specific diagnostic criteria for each of these conditions.

B. Description of the Other PDD Disorders

The following is a brief description of the other four pervasive developmental disorders:

1. **Pervasive Developmental Disorder, NOS** (PDD,NOS) is diagnosed when autistic symptoms are present but the full criteria for autistic disorder are not met. Therefore, persons diagnosed with PDD,NOS present with autistic symptoms, but typically are not as involved with the social and communication deficits as persons who meet the full criteria for autism. Generally, they are higher functioning and more responsive to treatment. PDD,NOS, along with Asperger's disorder, is thought by some researchers to be as common as autism.

2. **Asperger's Disorder** was first described by a German doctor, Hans Asperger, in 1944 (one year after Leo Kanner's first paper on autism). In his paper, Dr. Asperger discussed individuals who exhibited many idiosyncratic, odd-like behaviors. Unlike children with autism, children diagnosed with Asperger's disorder develop lucid speech before age four years and their grammar and vocabularies are usually adequate for normal conversation. Their speech is sometimes stilted and their repetitive voice tends to be flat and emotionless; their conversations revolve around themselves. Asperger's disorder is characterized by concrete and literal thinking. Persons with Asperger's disorder are usually obsessed with complex topics, weather, music, astronomy history, etc. Intellectual ability for most is in the normal to above normal range in verbal ability and in the below average range on tasks of visual-perceptual organization. Sometimes it is assumed that the individual who has autism and average mental ability has Asperger's disorder. However, it appears that there may be several forms of high-functioning autism, of which Asperger's disorder is only one form.

3. **Rett's Disorder** is a degenerative disorder which affects only females and usually develops between six months and 18 months of age. Some of their characteristic behaviors may include the following: loss of speech, repetitive hand-wringing, body rocking, and social withdrawal. Those individuals suffering from this disorder may be severely to profoundly mentally retarded. This disorder, along with childhood disintegrative disorder, is extremely rare.

4. **Childhood Disintegrative Disorder** (CDD) is included among the PDDs because these children apparently develop normally for two or more years before suffering a distinct regression in their abilities. Affected children lose previously acquired functional skills in expressive or receptive language, social skills or adaptive behavior including bowel or bladder control, play, or motor skills. Individuals with this disorder are rarer than persons with autism or one of the other PDDs; they exhibit the social, communicative and behavioral deficits observed in autism including loss of desire for social contact, diminished eye contact, and loss of nonverbal communication.

As research into autism continues, the diagnostic criteria published in DSM IV are continuing to be modified to reflect what is known about the different types of autism. As research has revealed the essential qualities of the disorder, clearer criteria allow more accurate diagnosis.

IV. Rates of Occurrence of Autism

A. Incidence Defined

Scientific measurement of the incidence of autism requires a carefully controlled study that captures the number of newly diagnosed persons with autism during a specified period of time and in a location with specified boundaries. The study would also have to identify the entire population of persons at risk, i.e., the number of new born infants in a specified location. To ensure the accuracy of the study, a large number of confounding variables would have to be controlled. Some of the variables that would have to be carefully controlled are accuracy of the diagnosis of autism, determining and counting the at-risk population, consistency of data collection across a large geographic area, subject finding, etc.

The most cited incidence statistic is that autism occurs in 4.5 of every 10,000 live births. This is based on large-scale surveys conducted in the United States and England. In addition, the estimate of children having autistic-like behaviors, i.e., when other disorders under the PDD umbrella are included, the incidence rate is 15 to 20 of every 10,000 live births. The scientific literature reports that autism is three times more likely to affect males than females. The gender difference is not unique to autism since many developmental disabilities have a greater male-to-female ratio.

B. Approach Used In This Study

In this report the incidence of autism is not measured. The unit of measure reported here is the rate of occurrence of persons with autism or other PDDs in the regional center and developmental center system during a specified period of time. The number of persons with autism, or other disability, varies daily by a small percentage because persons are leaving the system and newly eligible persons are entering. Because the number of persons in the system varies, data presented in this report were taken at the end of the year for years 1987 and 1998. The values of variables sampled at these two different times are compared to determine what significant changes may have occurred. The main question addressed in this report is whether the number of regional center eligible persons with a diagnosis of autism has increased compared to the other developmental disabilities, i.e., Cerebral Palsy (CP), Epilepsy (EP) and Mental Retardation (MR).

The findings and recommendations presented in the report are derived from analysis of demographic and Client Development Evaluation Record (CDER) data compiled at each of the 21 regional centers and forwarded electronically to the Department. The CDER file contains

consumer diagnostic and evaluation information recorded at the regional center or developmental center when a consumer is given a client development evaluation. This report focuses on the rate of intakes of persons with autism and other developmental disabilities into the regional center system over an 11-year period.

Autism is recorded on the CDER with one of three different codes - Level 1, Level 2 and Level 9. For the purposes of this study, a fourth code (Level 4) was created to capture four other types of PDD, including PDD,NOS, Asperger's Disorder, Rett's Disorder and Childhood Disintegrative Disorder. These PDD codes are recorded in the Mental Disorders section of the CDER. The four levels of classification used to search the Department's data files are listed accordingly:

- Level 1 - Autism, full syndrome
- Level 2 - Autism, residual state
- Level 4 - Composed of DSM IV, PDD codes 299.1, 299.80 and 299.88
- Level 9 - Autism suspected, not diagnosed

For the purposes of this report, data are reported using all four levels unless otherwise noted.

C. Early Start Program

Additionally, the Department provides early intervention services to infants and toddlers under three years of age who may be at risk or have significant developmental delay. In 1992, the Department began entering demographic data for children considered at-risk in the age range birth to three into a different database. Data describing these children are reported on the Early Start Profile. These data were not counted in this report as the majority of these children are not yet diagnosed with a developmental disability such as autism but are receiving services because of atypical development or language delay. As of January 6, 1999, there were 15,083 children receiving services through the Early Start program. The data reported here were taken from the total number of CDERs on the electronic file at the end of 1987 and 1998. The Department estimates that 95 percent of all active cases, including persons in the developmental centers, have a completed CDER on file. At the end of 1987 there were 80,389 CDERs on file. At the end of 1998, there were 129,169 CDERs on file.

V. Findings

A. Summary of the 1987 and 1998 Populations

Table 1 shows the number and percent change in the number of persons with autism and other PDDs counted from all four levels of CDER classification in the 11 years between 1987 and 1998. The population of persons with autism increased from 4.85 to 9.37 percent of the total

state wide client population. At the end of 1998 there were 12,780 persons, of all ages, with autism listed on the CDER. Autism as a percent of the total client population nearly doubled.

Table 1 - Number of Persons with Autism in 1987 and 1998

	1987	1998
Total Client Population	80,483	136,383
Persons with Autism (Levels 1, 2 & 4)	3,902	12,780
Percent of Total Client Population	4.85 %	9.37 %

Table 2 presents the total number and percent change between 1987 and 1998 for persons with autism, cerebral palsy, epilepsy and mental retardation. To maintain equivalency in the way each diagnostic condition is counted, only CDER classification Levels 1 and 2 for persons with autism are used in this table. Because some individuals have two or more of the four eligible conditions at the same time, all possible combinations of eligible conditions were used and a separate count was obtained for each condition or combination of conditions. For example, if an individual has cerebral palsy, epilepsy and mental retardation, that person would be counted three separate times, once for each separate condition to get the total for each separate condition.

Table 2 shows that the percent occurrence of persons with autism increased dramatically in comparison to the other conditions for the 11 years between 1987 and 1998. The rate of the increase is more than four times as great as the other diagnostic categories.

Table 2 - Percent Increase in Diagnostic Populations from 1987 to 1998

	1987	1998	Percent Change
Autism (All Combinations)	3,864	11,995	210.43%
Cerebral Palsy (All Combinations)	19,972	28,529	42.84%
Epilepsy (All Combinations)	22683	29,645	30.69%
Mental Retardation (All Combinations)	72,987	108,563	48.74%
Whole Population	80,483	136,383	69.46%

As one example of the increase in the number of persons with autism, between 12/31/97 and 12/31/98, there was a net increase of 1,685 persons with autism into the system. The population of persons with autism increased 16.3 percent in one year, not including persons with other PDD diagnoses. By the end of 1998, there were 785 persons in the system with a diagnosis of one of the (Level 4) PDD diagnoses, i.e., Asperger's, PDD,NOS or Rett's disorder.

Table 3 shows the percent change in occurrence of the other PDDs in comparison to autism. There was a 273 percent increase in the number of persons with autism between 1987 and 1998 and nearly a 2000 percent increase in the PDD categories. Table 3 also shows that as of December 31, 1998, there were 1,635 individuals coded on the CDER as "autism suspected, not diagnosed."

Table 3 - Autism and the Other PDDs Compared

	1987	1998	Percent Change
Autism (CDER Levels 1 & 2)	2,778	10,360	272.93%
Other PDD Types (CDER Level 4)	38	785	1,965.79 %
Autism Suspected, Not Diagnosed (CDER Level 9)	1,086	1,635	50.55 %

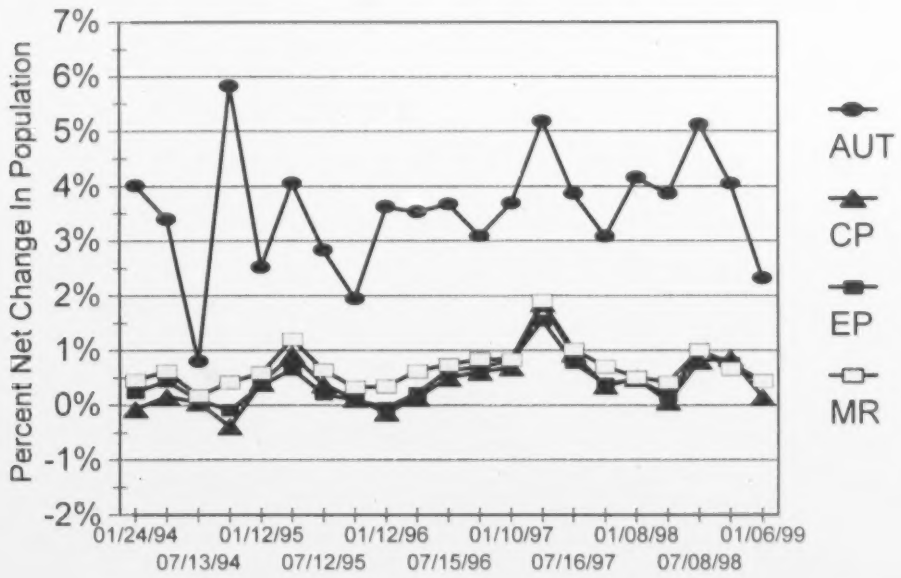
B. Changes in Population Rates of Intake

One method of recognizing if there is a change in the number of persons entering the system is to plot changes in the number of persons in the system across a number of years in order to identify trends and significant changes in the numbers. Figure 1 plots the 1991 population of persons (7,915) with autism by year of birth. Data points in Figure 1 do not show how many persons entered the system in a given year, but how many already in the system were born in a given year.

Figure 1 - Distribution of Birth Dates of Regional Center Eligible Persons with Autism

Beginning in August 1993, the Department began to publish quarterly summary reports of the number and characteristics of persons in the entire service delivery system. Figure 2 shows the quarterly net percent change in the number of persons with autism reported in the Statewide Client Characteristics summary compared to persons with CP, EP and MR. Comparison data run from August 1993 to January 1999. Figure 2 suggests that persons with autism were entering the system at a significantly faster pace than the other three eligible conditions at the beginning of 1994, or before 1994.

Figure 2 - Net Percent Change In Eligible Condition From August 1993 to January 1999



C. Changes in Autism Population Characteristics

The DSM IV reports that the male-to-female ratio among persons with autism is "four to five times higher in males than in females." CDER data support this claim. Males represent 79.9 percent of the population of persons with autism compared to 20.1 percent for females. In 1987, the percent of males was 74.6 versus 25.4 percent for females. There has been a 5.3 percent increase in the proportion of males in 11 years.

Age distribution of the population of persons with autism is shown in Figure 3. By the end of 1998, nearly half of the population of persons with autism consisted of children between birth and nine years of age. What is more important, during the 11-year period between 1987 and 1998, the median age of the population of persons with autism drops from 15 years to nine years. Clearly, more and younger children are entering the system.

Figure 3 - Age Distribution for Autistic Population in 1987 and 1998

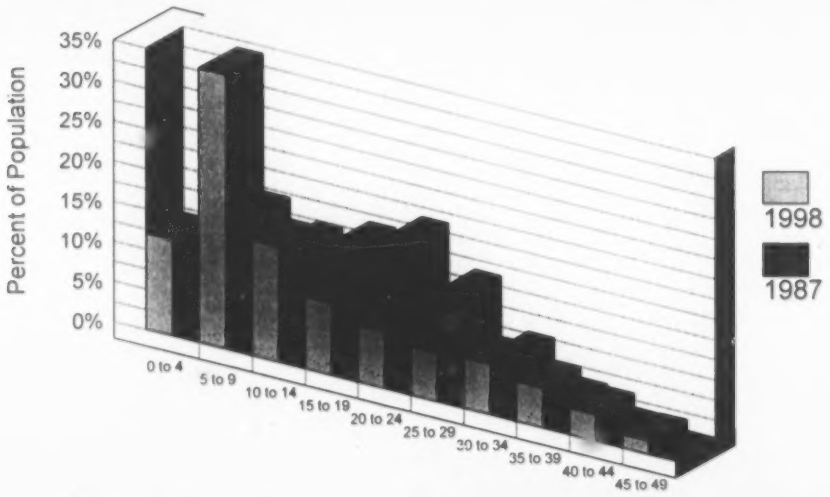


Figure 4 shows age at the time of intake into the regional center. Figure 4 shows that persons with autism who are four years or younger account for the greatest increase in new intakes. By the end of 1998, more than half (55 percent) of all persons with autism were made eligible before their fourth birthday. By comparison, only about one third (34.6 percent) of the 1987 population were enrolled by age four. In 1987, 30.1 percent of the intakes were in the 10 to 19 year age range compared to 17 percent in 1998. A one year comparison between 1997 and 1998 shows that the greatest relative increase in new intakes was in the birth to four year group (See Figure 4).

Figure 4 - Age At Intake Into Regional Center

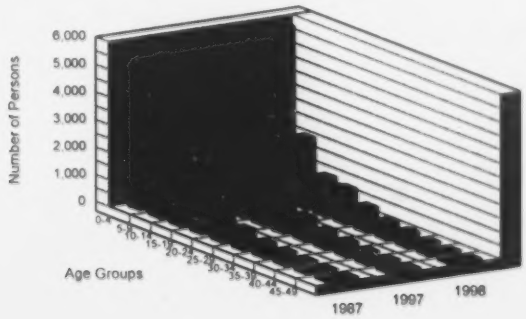
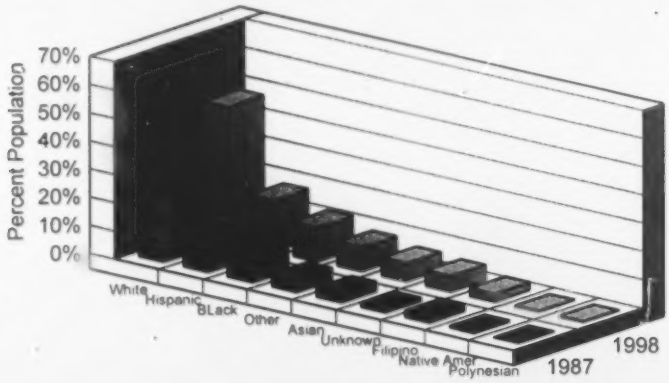


Figure 5 shows ethnicity for the population of persons with autism. Compared to the total population, ethnicity of persons with autism generally conforms to the percentage representations of each ethnic group in the California population. Notable changes in ethnicity during the 11 years of this study show a 13.6 percent drop in White persons with autism and a 6.5 percent increase in the Hispanic population.

Figure 5 - Ethnicity Among Persons with Autism



Cognitive ability varies greatly among persons with autism. Figure 6 shows the distribution of intellectual abilities for the population of persons with autism. Figure 6 shows that 42 percent of persons with autism function intellectually above the level of mental retardation. Nearly 20 percent are in the mild range (IQ 55 to 70). The remaining 37.7 percent have moderate or lower levels of intellectual ability. There was a significant change in the percent of persons with no mental retardation during the 11-year time difference between samples. The current population of persons with autism reflects significantly more persons with no or mild mental retardation and far fewer persons with severe to profound mental retardation.

Figure 6 - Mental Ability and Autism

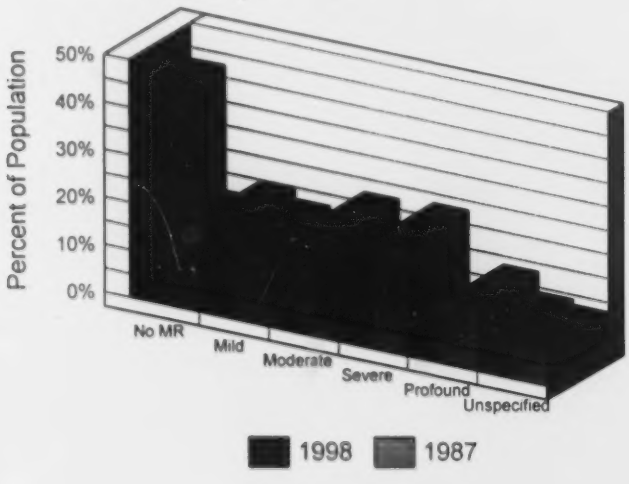
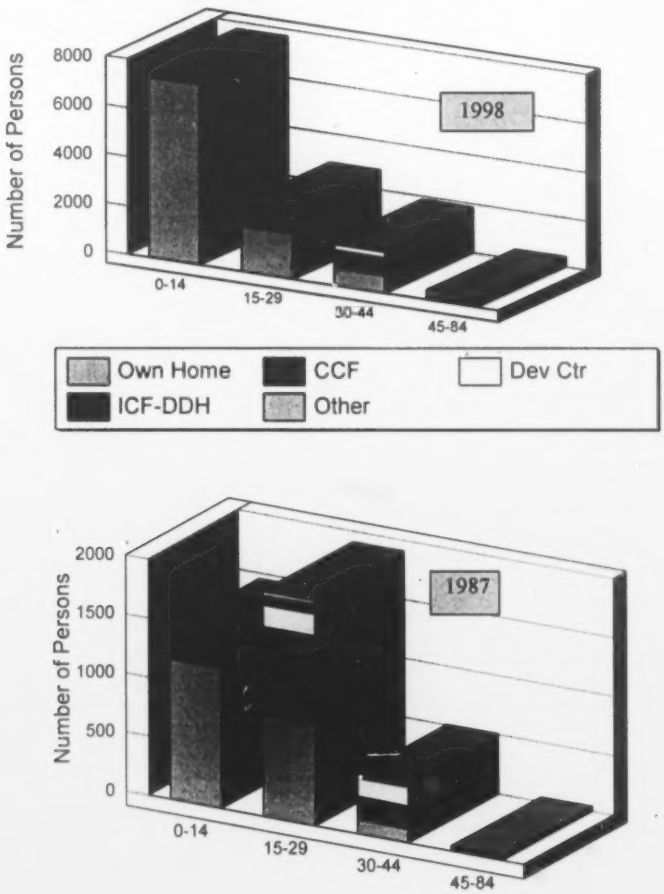


Figure 7 shows type of residence for the entire number of persons with autism categorized by age groups for the years 1998 and 1987. Ninety four percent of persons with autism of all ages live in one of two types of residence: own home and community care facility (CCF). The remaining 6 percent live in the developmental center, ICF-DDH or other[1] type of residence. In 1998, 79 percent (10,035) of persons of all ages lived at home with their families or in an independent living setting. In 1987, 55 percent (2,151) lived at home. The greatest percentage increase (19 percent) between 1987 and 1998 was in the Own Home, birth to 14 age group. As more, and younger, persons with autism came into the system, they were more likely to stay at home. The percentage of persons in the age range 15 to 29 living in CCFs decreased in 1998.

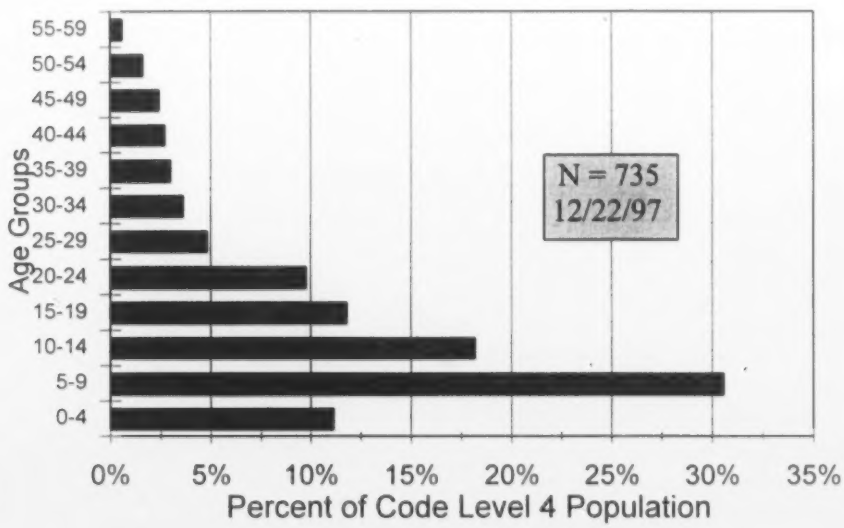
Figure 7 - Residence Type By Age Group



[1] The "Other" category in Figure 8 includes ICF-DD, ICF-DDN, SNF and psychiatric hospitals. The total number of person in the Other residence category total 19.

Figure 8 shows the age distribution of persons with one of the following diagnoses: Asperger's, PDD,NOS, Childhood Disintegrative Disorder or Rett's. All four of these PDDs were combined into one sample taken on 12/22/97. Just more than 30 percent of these other PDDs were in the five to nine year age range. The second highest percent (18 percent) of that group was in the 10 to 14 age range. Nearly half (48.6 percent) of the entire sample was between five and 14 years of age.

Figure 8 - Age Distribution of Asperger's, PDD,NOS, Rett's & CDD



VI. Discussion of Findings

A. An Emerging Group of Consumers

Data covering a period of eleven years, beginning in January 1987 and continuing through December 1998, show that the number of persons with autism, not including other PDD diagnoses, grew faster than the number of persons with other developmental disabilities. Significantly greater numbers of persons with autism are entering the regional center system. In just the past year, there were 1,685 persons with autism taken into the system. This number of persons far exceeded the expected number determined by traditional incidence rates. Rough estimates of the expected number of persons that could potentially be diagnosed annually with autism can be made by multiplying the number of live births in one year in California by the published incidence rate(s). In 1998 the Center for Health Statistics, Department of Health Services estimated 526,501 live births statewide in California. Using DSM IV incidence rates of 2 to 5 persons per 10,000 live births yields an estimate of 105 to 263 persons per year. During

calendar year 1998 there were 11,995 persons with autism or one of the other PDDs and an additional 1,635 persons suspected of having autism. Using published incidence rates that include autism, Asperger's and PDD,NOS, which range from 15 to 20 cases per 10,000 live births, an estimated 790 to 1,053 persons per year could be diagnosed with autism or one of the other PDDs. The number of new intakes has exceeded the annual estimate of persons likely to be diagnosed with autism for the past few years.

Estimates suggest that, compared to the other disabilities, net growth in the number of persons with autism is about 3 percent greater each year. Because the current trend has continued for the past several years, it suggests that relatively faster growth in the number of eligible persons with autism may continue well into the next century. Other government reports, such as the Nineteenth Annual Report to Congress on the implementation of the Individuals with Disabilities Education Act, document substantial increases in autism. Between fiscal years 1994-95 and 1995-96, the 1997 Nineteenth Annual Report to Congress states that the number of children with autism grew by 27.2 percent and was one of "the largest relative increases."

B. Summary of Changes in the Current Population

The data show that younger children constitute the majority of new intakes. A rapidly expanding subpopulation of children diagnosed with one of the other PDDs has emerged since the creation of the PDD diagnoses. This population grew from 38 individuals in 1987 to 785 in 1998. There are an additional 1,635 individuals "suspected" of having autism and 13,496 more undiagnosed children in the early start program. An undetermined percentage of individuals in these groups, upon clarification of their diagnostic status, will further increase the number of persons with autism and/or PDD.

Compared to client characteristics of 11 years ago, the population of persons with autism is younger, exhibits no or milder forms of mental retardation, is more likely to live at home and is more likely to receive an earlier diagnosis. Nearly half of the 1998 population is less than nine years of age compared to only one fourth of the population in 1987.

The number of persons who function intellectually above the range of mental retardation increased from 16 percent to 43 percent, a 26 percent point increase in 11 years. The increases in intellectual gains were relatively broad. Level of intellectual functioning in 29 percent of the population of persons with autism shifted from the moderate range (IQ 40 to 54) to the mild range (IQ 55 to 70) of mental retardation.

By the end of 1998, an individual's chances of remaining in his/her own home increased significantly for children up to 14 years. In the birth to 14 year group, 74 percent live at home. In the 15 to 29 years old group, the greatest proportion of persons with autism live in a CCF.

Except for a 14 percent drop in the number of White persons and a 7 percent increase in Hispanic persons with autism, ethnic representation did not change appreciably in 11 years. Overall, ethnic representation roughly paralleled the state census.

VII. Conclusions

This report was not an investigation of incidence, but was rather an official counting and reporting of the number of persons with autism and other developmental disabilities served by the regional center system over time. The Department's CDER data provide preliminary evidence that support the following two general statements: (1) the number of persons entering the system with autism has increased dramatically over the past 11 years relative to the other three developmental disabilities, and (2) the accelerated rate appears to be sustaining an upward trend which will continue into future years. In light of the information presented in this report, it is reasonable to assume that the population of persons with autism will continue to rise faster, relative to the other developmental disabilities, for the next several years.

The quality and type of information examined in this report were not suitable for measuring incidence in the population of persons with autism. Ascertaining the incidence for autism and the other PDDs will require carefully controlled research. Furthermore, it is far beyond the capability of this Department to undertake such studies. Independent study of the factors that contribute to increases in the population of persons with autism needs to be conducted by academic institutions with the experience and knowledge necessary to conduct such research. Examples of such institutions are Medical Investigation of Neurodevelopmental Disorders (MIND Institute) within the University of California system.

The cause(s) of the increase in the population of persons with autism served by the regional center over the past 10 years is unknown. The sheer complexity of this phenomenon prevents any clear conclusions about the exact determinants of the increase. Speculation about the rise in numbers is abundant, but such speculation is not based on scientific research and typically leads to debate and controversy when offered as a cause. In fact, rampant speculation followed by acrimonious debate about the causes of an increase in autism has provoked one congressman, Representative Christopher H. Smith, to introduce legislation (H.R. 274) aimed at providing a greater understanding. Representative Smith's bill addresses the causes and occurrence of autism and related pervasive developmental disabilities. This measure, entitled the Autism Statistics, Surveillance, Research, and Epidemiology Act of 1999 would provide additional funding for the Centers for Disease Control and Prevention to create a network of epidemiological research centers across the country.

What we do know is that the number of young children coming into the system each year is significantly greater than in the past, and that the demand for services to meet the needs of this special population will continue to grow. If present rates of intake continue, there will be a need for: (1) greater emphasis on long range planning to develop suitable methods of delivering services, (2) strategies for development of new and abundant resources; (3) clinical training of regional center personnel in diagnostic and treatment standards necessary to adequately advise parents and (4) creation of forums for information exchange and collaboration between providers and the families of children with autism. In conclusion, there is a real need to accelerate multi-discipline, multi-faceted research efforts in this area.

VIII. Appendix

A. Diagnostic criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic criteria for 299.80 Rett's Disorder

A. All of the following:

(1) apparently normal prenatal and perinatal development

(2) apparently normal psychomotor development through the first 5 months after birth

(3) normal head circumference at birth

B. Onset of all of the following after the period of normal development:

(1) deceleration of head growth between ages 5 and 48 months

(2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)

(3) loss of social engagement early in the course (although often social interaction develops later)

(4) appearance of poorly coordinated gait or trunk movements

(5) severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic criteria for 299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

(1) expressive or receptive language

(2) social skills or adaptive behavior

(3) bowel or bladder control

(4) play

(5) motor skills

C. Abnormalities of functioning in at least two of the following areas:

(1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)

(2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)

(3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

Diagnostic criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(2) failure to develop peer relationships appropriate to developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

(4) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(2) apparently inflexible adherence to specific, nonfunctional routines or rituals

(3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"--presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

B. Early History of Autism

Our understanding of autism has evolved from a crude and inaccurate description to a more refined and legitimate scientific knowledge. In the beginning, and partly based on Kanner's perception of autism, it was believed that persons with autism had "good cognitive potentialities." The myth of the autistic child possessing a latent genius endured for several years and has caused great distress for family members and teachers who have nearly always failed to find the key to "unlock" the alleged genius. Another misconception linked to Kanner's belief, and later perpetuated by Bruno Bettleheim, was the view that it was the parents' behavior, particularly the mother's, that caused the autistic condition. Kanner observed that parents in his clinic were from upper-middle-class backgrounds and had a cold manner in dealing with their autistic children. Bettleheim, in the 1960s, picked up this theme and built a theory of the nature of autism in which the emotional coldness of parents was the central cause. The term "refrigerator mom" was used to describe the mother's hopelessness, despair, and apathy which, when projected onto the child, caused the child to withdraw from reality. Bernard Rimland, a parent and founder of the Autism Society of America, in the late 1960s played an important role in changing the prevailing psychoanalytic view of autism that had been popularized by Bettleheim. Rimland put forth a neurologically based approach, which opened the door for the burgeoning biomedical research of today.

The abandonment of a psychoanalytic approach to treating autism led to the rapid growth of research and treatment based on behavioral, cognitive-developmental, and recent medical research. Beginning in the 1960s and continuing through the present, psychological research was applied to the learning of children with autism. Today the integration of basic behavioral research and treatment programs into many different treatment settings has led to substantial knowledge and improved services. Applied behavior analysis has led to a much broader emphasis on educational programming and the need for early teaching of practical skills for community living throughout the life span. The availability and effectiveness of behavioral support services, in conjunction with the concept of normalization and the least restrictive environment, have contributed to the reversal in a trend to institutionalize children with autism. Before effective behavioral support services were so commonplace, children with autism, typically by age nine or 10, were so out of control their parents were compelled to place them in institutions. Unfortunately, the medical profession, faced with little or no alternatives, endorsed the idea of institutionalizing children during the 1960s and 1970s.